

# The Roles of the Family in Making Health Care Decisions for Incompetent Patients

*Leslie P. Francis\**

## I. INTRODUCTION

This Article is about the roles of the family in making health care decisions for incompetent patients. It argues that complex moral reasons call for the participation of families in decision making for incompetents. However, these moral reasons do not support a single model of the family's role for all incompetents. Rather, they suggest important differences among the roles family members should play in decision making for different kinds of incompetent patients: formerly competent adults, never competent adults, or infants and children.

Briefly summarized, the differences in roles are as follows: First, in making decisions for formerly competent adults, the family's principal role should be to help with the recognition of the patient as autonomous chooser, insofar as that can be achieved. Thus, the family may be called upon to provide information about the patient, such as the patient's expressed preferences about health care decisions (when they are available), values, and approaches to making decisions. Second, in making decisions for never competent adults, the family's principal role should be that of concerned advocate for the interests of the patient. Here, the family attempts to ensure that the patient's interests are understood and considered. Third, in making decisions for infants and young children, the family's role is to construct, as well as to pursue, a reasonable account of the child's best interests. These differences among roles are important, and developing them will be the task of the first two parts of this Article.

The third part of this Article will consider how families have been legally included in—or banished from—health care decision making for the same groups of incompetent patients. Recent American law—at least since the potentialities of modern medical

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\* Professor of Law, Associate Professor of Philosophy, University of Utah.

care have come under judicial scrutiny—has confronted a remarkable range of situations in which the roles of families have been at issue. Unfortunately, however, the law has been more than a little unclear about how to treat families. Trends, of course, are always difficult to summarize, but there have been notable instances in which families have been allowed a great deal of latitude in decision making for formerly competent and never competent adult patients. However, families have been given little say in decision making for young children and particularly for infants. The law, in short, may be morally backwards.

Several introductory comments are important to avoid misunderstanding the argument which follows. First, there are well-known problems with family decision making for incompetents, which are largely bypassed in this discussion. Families may have conflicts of interest. The most obvious conflicts are money and time; the continuing need for care may drain family finances or become a constant burden. But there are other kinds of conflicts as well, for example, emotional stress: families may prefer the patient's death to the daily renewal of grief as a disabled relative continues to survive. Even if these conflicts of interest are relatively minimal, families may have difficulty shouldering the responsibilities of decision making. It may seem unfair—a genuine abdication—for health care providers to expect families to take responsibility for difficult decisions. Shifting the burdens of decision making to the family may seem particularly problematic if families are coming to terms with the sudden shock of illness or disability. It may seem downright cruel if family members have themselves been injured or physically affected by the events of the patient's illness or injury, such as luckier (and possibly guilt-ridden) survivors of a devastating accident or a mother who has just given birth to a compromised infant. Some of these concerns—time, money, or emotional stress—are likely to be present when families are involved in the care of any of these patients. Other concerns—the shock of confronting an unexpectedly disabled newborn, together with the mother's own physical state—may apply differently to different types of patients and in different types of circumstances. Although this discussion does not focus on the general problems with family decision making, they should not be forgotten. Particularly severe risks of conflicts of interest, for

example, may in certain cases justify different legal treatment of the family's role.

Second, this discussion will largely bypass issues in defining the family. Is "the family" defined by biological relationships and, if so, which ones? Is it defined by legally recognized relationships, including some biological relationships but also including adoption and marriage? Can individuals construct their own familial relationships, such as through surrogacy contracts or same sex marriages?<sup>1</sup> State statutes authorizing family members to serve as surrogate decision makers, for example, typically include a limited list of family members in priority order.<sup>2</sup>

## II. WHY THE FAMILY?

Several reasons support giving families privileged roles as surrogate medical decision makers. This section surveys these reasons, in light of three questions. First, why does the reason support a special role for the family as surrogate decision maker? Second, how strong is the reason? More precisely, does the reason provide just an argument for consulting the family? Or, is it strong enough to support a presumption in favor of the family? Is that presumption rebuttable or irrebuttable? Third, what is the nature of the family's role? Is the family involved as a source of information? As decision maker in terms of the patient's interests? As patient advocate? The survey of reasons begins with patient-centered concerns and then turns to family-centered reasons and the interests of society.

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1. For a discussion of a functional approach to defining the family, see Martha Minow, *Redefining Families: Who's In and Who's Out?*, 62 U. COLO. L. REV. 269 (1991).

2. Utah's statute, for example, specifies the following ordered list of surrogate decision makers: holder of special power of attorney appointed by the patient, previously appointed legal guardian, spouse (if not legally separated), parents or surviving parent, child at least 18 years old (or a majority of reasonably available children at least 18 years old), nearest reasonably available living relative at least 18, and legal guardian appointed for the purpose of the health care decision at issue. UTAH CODE ANN. § 75-2-1105(2)(b) (Supp. 1992). An innovative New York proposal is to allow family members to agree upon a designated surrogate to replace the order which would otherwise apply. NEW YORK STATE TASK FORCE ON LIFE AND THE LAW, WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY app. A, at 252-53 (1992) [hereinafter NEW YORK STATE TASK FORCE].

### A. *The Patient*

As the theory of decision making for incompetent patients has been developed, two standard approaches have emerged: an approach that aims to reproduce the patient's own choices and an approach that aims to further the patient's best interests. The attempt to reproduce the patient's own choice is seen as a recognition of the continued autonomy of a formerly competent patient and is preferred when the patient's choices can be known or reconstructed. The "best interests" approach is preferred for patients whose choices are unknown or for patients who have never been able to make competent choices.<sup>3</sup> Either of these approaches to decision making for incompetents requires accurate information, a need that may lead to the family.

#### 1. *Autonomy and Substituted Judgment*

Suppose that the aim is to try to replicate what the incompetent patient would have chosen. Then, one important source of information is the patient's earlier directions about future eventualities. Only a small percentage of patients take advantage of formal legal mechanisms for directing health care in advance. However, with recent publicity and the Patient Self-Determination Act ("PSDA")<sup>4</sup> this percentage may increase. If there are reasons to doubt the accuracy of earlier directives, if the earlier record is nonspecific or vague, or if there is no earlier record, information will be needed that permits reconstruction of what the patient might have chosen.<sup>5</sup> For this reconstruction, it may be helpful to

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3. See, e.g., *In re Jobes*, 529 A.2d 434, 452-61 (N.J. 1987) (Handler, J., concurring) (examining "substituted judgment" and "best interest" principles); ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 122-33 (1989) (discussing "best interest" standard). John Robertson has recently raised provocative questions about whether the choices of the formerly competent patient ought to be favored over the best interests of the now incompetent patient. John A. Robertson, *Second Thoughts on Living Wills*, HASTINGS CENTER REP., Nov.-Dec. 1991, at 6.

4. Patient Self-Determination Act, Pub. L. No. 101-508, § 4206, § 4751, 104 Stat. 1388, 1388-115, 1388-204 (1990) (codified at 42 U.S.C.A. §§ 1395cc, 1396a (West 1992)). For a discussion of difficulties with utilization of advance directives and implementation of the PSDA, see John La Puma et al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402 (1991).

5. For a discussion of some of the ethical difficulties in allowing an earlier directive

have anecdotes of the patient working through actual or hypothetical medical decisions. More general information about the patient's values, methods of assessing information, or attitudes towards decision making could also be utilized in the reconstruction.<sup>6</sup>

In the litigated cases that attempt to reconstruct what the patient would have chosen,<sup>7</sup> families often report earlier discussions with the now-incompetent patient about health care decision scenarios. These discussions frequently are reported as reactions to the illnesses of other family members or friends. For example, when her husband was hospitalized with cancer, Mary O'Connor told her daughter that "she never wanted to be in a similar

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to guide a patient's later care, see BUCHANAN & BROCK, *supra* note 3, at 152-89; Robertson, *supra* note 3, at 6-9. For a discussion of the possible vagueness of advance directives and a proposal for more precision, see Linda L. Emanuel & Ezekiel J. Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 261 JAMA 3288 (1989). For a discussion of physicians' and spouses' potential inaccuracy in predicting preferences of ill patients, see Allison B. Seckler et al., *Substituted Judgment: How Accurate are Proxy Predictions?*, 115 ANNALS INTERNAL MED. 92, 95-97 (1991); Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY M115 (1988). For a discussion of advance directive statutes and the easy revocation of these documents, see Leslie P. Francis, *The Evanescence of Living Wills*, 24 REAL PROP., PROB. & TR. J. 141 (1989). To take one typical example of how a state handles some of these difficulties, the Utah statute provides both that the desires of a competent declarant override an advance directive, UTAH CODE ANN. § 75-2-1108 (Supp. 1992), and that an advance directive can be revoked by oral statements of intent in the presence of a witness over 18 years of age who then signs a dated written instrument documenting the expression of intent. *Id.* § 75-2-1111(1)(c). As advance directives come into more general use, particularly if the PSDA encourages patients to complete advance directives under less than ideally thoughtful circumstances, it can be expected that there will be more doubts about their accuracy, and that family members will be a likely source of these doubts.

6. See, e.g., Eric T. Juengst & Carol J. Weil, *Interpreting Proxy Directives: Clinical Decision-Making and the Durable Power of Attorney for Health Care*, in ADVANCE DIRECTIVES IN MEDICINE 21-37 (Chris Hackler et al. eds., 1989).

7. The legal term characterizing this effort is "substituted judgment." See, e.g., *Jobes*, 529 A.2d at 456-57 (Handler, J., concurring) (discussing theory of substituted judgment). Sometimes courts are confused about this test, applying it to those who have never been competent. For example, in *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977), the court applied the substituted judgment standard in deciding to withhold chemotherapy from a 67-year-old man profoundly retarded since birth. The *Saikewicz* decision has been widely criticized for confusing the purpose of substituted judgment. See BUCHANAN & BROCK, *supra* note 3, at 113-15. The pure idea of substituted judgment is to try to reconstruct what the patient would have chosen from what is known about how the patient made decisions. The surrogate decision maker, in exercising substituted judgment, tries to stand in for the incompetent by imaginatively reconstructing what the patient would have chosen from the information that is available about the patient. *Id.* at 117-22. To the extent that little information is known, this process becomes increasingly speculative and may be given less weight as a result. *Id.*

situation and that she would not want to go on living if she could not 'take care of herself and make her own decisions.'<sup>8</sup> After her own heart attack, Mrs. O'Connor also told her daughter that "she was very glad to be home, very glad to be out of the hospital, and hope[d] she would never have to be back in one again and would never want any sort of intervention[,] any sort of life support systems to maintain or prolong her life."<sup>9</sup>

Other typical examples of family reports involve discussions about the publicized but abstract fates of strangers. In *In re Swan*,<sup>10</sup> a case of a seventeen-year-old in a persistent vegetative state after an automobile accident, the patient's mother described a conversation with her son about a highly publicized termination-of-treatment decision. In discussing what it meant to be a "vegetable," she explained that it meant requiring total care. Swan replied, "If I can't be myself . . . no way . . . let me go to sleep."<sup>11</sup> In a more concrete but similar account, Swan's brother told of their visit to a comatose friend just eight days before his brother's accident. Reacting to the visit, Swan had remarked to his brother that "I don't ever want to get like that . . . I would want somebody to let me leave—to go in peace."<sup>12</sup>

Somewhat vaguer reports are found in the *Jobes* case. Nancy Jobes is described as telling her first cousin that she wouldn't want "heroic measures" taken in the case of an accident and as telling her husband that "she would not want to be kept alive under Karen Quinlan's circumstances."<sup>13</sup> In still other cases, family members relate general perspectives on medical care—"she disliked going to doctors"<sup>14</sup>—or style of living—"Bertha Colyer was a very independent woman."<sup>15</sup> Family members may also report religious convictions and their guidance for decisions about care.<sup>16</sup>

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8. *In re Westchester County Medical Ctr.*, 531 N.E.2d 607, 611 (N.Y. 1988).

9. *Id.*

10. 569 A.2d 1202 (Me. 1990).

11. *Id.* at 1205.

12. *Id.*

13. *Jobes*, 529 A.2d at 442.

14. *In re Welfare of Colyer*, 660 P.2d 738, 748 (Wash. 1983).

15. *Id.*

16. *E.g.*, *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626, 632 (Mass. 1986) (stating that surrogate decision maker "went through long and agonizing research, reflection, and prayer," and discussed decision with clergy).

Some courts are quite willing to rely on these familial stories. For example, in authorizing the withdrawal of treatment from Bertha Colyer, the Washington Supreme Court commented: "Given the unanimity of the opinions expressed by Bertha's closest kin, together with the absence of any evidence of any ill motives, we are satisfied that Bertha's guardian was exercising his best judgment as to Bertha's personal choice when he requested the removal of the life support system."<sup>17</sup>

Other courts, however, express doubt about the specificity or reliability of these familial stories as a basis for understanding what the patient would have chosen. The New York court, for example, pointed out that Mary O'Connor had not explicitly discussed medically assisted nutrition and hydration with her daughter; nor had she expressed attitudes towards pain or comfort care.<sup>18</sup> In the *Jobes* case, the New Jersey court refused to rely on the family's evidence as a basis for a reconstruction of what Nancy would have chosen: "All of the statements about life-support that were attributed to Mrs. Jobes were remote, general, spontaneous, and made in casual circumstances. Indeed, they closely track the examples of evidence that we have explicitly characterized as unreliable."<sup>19</sup>

Courts that insist on clear and convincing evidence of the patient's wishes before a termination of treatment decision can be effectuated, such as New York, may be especially skeptical about the status of these familial reports.<sup>20</sup> But skepticism is not limited to courts which insist on a high evidentiary standard; a California Court of Appeals, for example, has pointed out the unreliability of the patient's informal statements, made perhaps years earlier, when constitutional rights are involved: "It would be a dangerously unpredictable precedent."<sup>21</sup>

Thus, when the effort is to replicate what the patient would have chosen and thereby recognize the patient's autonomy, the reason for family involvement is the likelihood that the family will

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17. *Colyer*, 660 P.2d at 748.

18. *Westchester County Medical Ctr.*, 531 N.E.2d at 611.

19. *Jobes*, 529 A.2d at 443.

20. *E.g.*, *Cruzan v. Harmon*, 760 S.W.2d 408, 424 (Mo. 1988) (en banc) (stating that similar to *Jobes*, statements used to determine Nancy Cruzan's intent are unreliable) (citing *Jobes*, 529 A.2d at 443).

21. *Drabick v. Drabick*, 245 Cal. Rptr. 840, 856 (Ct. App. 1988).

have good information about the patient's choices, preferences, or values. In these cases, the reason for family involvement is only as strong as the likely evidentiary value of the family's knowledge. When family members are the only good sources of this kind of information, they may appear uniquely positioned to help in decision making. But this unique positioning is contingent on the accuracy and exclusiveness of the family's information. Thus, the family's unique position provides at best a good reason for consulting the family but not an irrebuttable presumption in favor of family involvement. On the other hand, if the patient has exercised a durable power of attorney to select a family member (or someone else) as decision maker in the case of incompetence, there would be a much stronger reason for recognizing the authority of the surrogate, rebuttable only by a showing that the appointment of the surrogate itself was flawed.<sup>22</sup>

## *2. The Patient's Best Interests*

Information about the patient's interests is required for application of the best interests standard. Here, too, the family may have important information. Court decisions applying the "best interests" standard have done little to provide a general theoretical account of what they mean by "interests." Perhaps the fullest judicial account was given by the Arizona Supreme Court: interests involve "such objective criteria as relief from suffering, preservation or restoration of functioning, and quality and extent of sustained life."<sup>23</sup> The more theoretical account relied on by the Arizona court was provided by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: "An accurate assessment [of interests] will encompass consideration of the satisfaction of present desires, the opportunities for future satisfactions, and the possibility of developing or regaining the capacity for self-determination."<sup>24</sup> The

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22. For a recognition of the importance of special powers of attorney for health care, see *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841, 2857-58 (1990) (O'Connor, J., concurring).

23. *Rasmussen v. Fleming*, 741 P.2d 674, 689 (Ariz. 1987) (en banc) (footnote omitted).

24. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREAT-



ability to experience pleasure and the receipt of health care with the potential to restore function are typically regarded as in a patient's interests, and the experience of pain or uncomfortably intrusive health care are typically regarded as not in a patient's interests.<sup>25</sup>

The family may be able to provide information about the patient's wants and, in some cases, about what means will help to satisfy them. In reported decisions, families often indicate the extent to which continued care is painful or disturbing to the patient or, on the other hand, is well tolerated. For example, from the age of five, Barbara Grant suffered from Batten's disease, a genetic disease causing progressive neurological deterioration. Her mother, seeking to have life support withheld during the final stages of the illness, described her daughter's dislike for taking medicine, using a cane, having suction tubes used on her, and her dislike for the medical staff.<sup>26</sup> In another reported decision, John Storar was fifty-two years old, with a mental age of about eighteen months.<sup>27</sup> He suffered from bladder cancer and was expected to live four to six months with regular blood transfusions. His seventy-seven-year-old mother, who lived nearby and visited him daily, observed that the transfusions disturbed him and requested to have them discontinued.

Despite the likelihood that family members will have information that is crucial to assessing what is in the patient's interests, application of the best interests standard also may require information that is not particularly likely to be within the scope of the family's special knowledge. For example, the standard requires an objective assessment of the benefits and risks for the patient of continued care, an assessment that may require quite technical medical understanding.<sup>28</sup> In applying the standard, courts thus may give weight to medical testimony about the likely results of treatment. To the extent that an assessment of interests requires factual judgments that are beyond the family's particular expertise, courts may be less likely to turn to the family and more

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MENT RESEARCH 135 (1983).

25. See *Rasmussen*, 741 P.2d at 689.

26. *In re Guardianship of Grant*, 747 P.2d 445, 448 (Wash. 1987) (en banc).

27. *In re Storar*, 420 N.E.2d 64, 68 (N.Y. 1981).

28. See, e.g., *Jobes*, 529 A.2d at 457 (Handler, J., concurring) (decision maker must consider needs, risks, and benefits to affected person).

likely to turn to expert sources, particularly physicians, for relevant information.<sup>29</sup>

In addition to their knowledge, family members may also be better motivated than others to be sure that standards for decision making—either substituted judgment or the patient's best interests—are applied carefully and accurately. Family members may be motivated to seek out information about the patient's expressed preferences. Similarly, they may be more motivated than others to pursue the information needed to decide what is in the patient's interests—for example, information about various sources of financing for care or about alternative facilities for treatment.

The *Jobes* decision is an excellent example of a court's reliance on the family's care and concern for the patient:

Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort, care, and best interests and they who treat the patient as a person, rather than a symbol of a cause.<sup>30</sup>

As the *Jobes* court notes, familial caring may be directed to the needs of the individual patient, rather than more abstractly towards a value such as preserving life or providing good medical care. Caring may also motivate families to be persistent advocates for the patient's interests, doggedly insisting that the patient receive attention, comfort, respect, and any care that might prove beneficial.

In addition to their knowledge and motivation, families are likely to be important to the success of various forms of care for incompetent patients. Families are the most likely caregivers for

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29. See, e.g., *id.*, at 460 (Handler, J., concurring) (suggesting that in ambiguous cases, decision maker should consult doctors, government and institutional representatives, and people with religious or ethical training). For a defense of this approach, see Michele Yuen, Comment, *Letting Daddy Die: Adopting New Standards for Surrogate Decisionmaking*, 39 U.C.L.A. L. REV. 581, 608-631 (1992).

30. *Jobes*, 529 A.2d at 445 (citations omitted).

the debilitated. Their help is also likely to be needed in implementing various forms of therapy, particularly as patients are discharged more quickly from care facilities. For example, the participation of family members may be important to rehabilitation programs for stroke victims or educational programs for disabled children. Thus, if families become invested in the decisions about care, these decisions are more likely to work out well for patients. Each of these links to the family, however—knowledge of interests, care and concern, and involvement in therapy—are contingent and may well not apply in specific family circumstances.

### *B. The Patient's Future*

To this point, the discussion of patient-centered reasons has assumed a patient with settled choices, preferences, or interests—someone who has become a developed person, although perhaps only to an extent limited by medical events. But some patients, especially young children, do not have a full range of established choices or even readily predictable interests. There is not as yet a template of choices or interests of the patient on which to base decisions. The template remains to be developed, if possible. Health care decisions, like other decisions that affect the fates of young children, will shape preferences and interests and thus will help create the person the child becomes. Decisions for children therefore may entail weighing options for very different kinds of persons and lives.

This contrast between adults and very young children is, to be sure, a matter of degree rather than absolute. As children mature, their interests become clearer and more settled. Most young children do have interests related to occurrent preferences, as well as to how they will develop, for example, interests in being fed or free from pain. On the other side, the interests of adults are open to change in the future and will to some extent be shaped by the medical choices that are made. Therapeutic options that result in loss of a limb, damage to sight or hearing, or infertility, may open—or close—very different futures for patients, and their choices and interests may shift in response. Nevertheless, for adult patients these choices take place against a template of already-shaped preferences about physical activity, music, or bearing

children. For young children, the individualized template is far less clear.

This contrast between the relative open-endedness of the preferences of children and the relative development of the preferences of adults has important implications for the role of the family in health care decision making. The approach to adult decision making, as it has been developed in contemporary bioethics and as it was discussed in the preceding section, is grounded in several important assumptions of liberal theory. The starting place for analysis is the individual (in this case, the patient). A very important moral task (if not the most important moral task) is to respect the patient's autonomy as far as possible.<sup>31</sup> Autonomy is respected either by letting the patient choose, or by relying upon an already-developed template of values, preferences, interests, and choices. When autonomy is not a possibility, the patient is assumed at least to have individualized interests that are to be the basis of decision making.

For children, in contrast, the background template is yet to be constructed. A theory of health care decision making must include an account of how the background template is to be filled in, including a view about the roles for parents or other family members. There are, of course, many different views about the roles of parents in shaping the preferences and interests of their children. One basic division is whether the claims of parents or the claims of children are the most fundamental to a theory of parent-child relationships.<sup>32</sup> Another is the meaning and value of autonomy for the developing child.<sup>33</sup> For those who would regard autonomy as an important value, still another issue is the role of parents in fostering autonomy. With respect to parent-child relations, perhaps the prevailing liberal views are that the claims of the individual child are foundational and that children should

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31. The canonical liberal text in contemporary bioethics likely is THOMAS L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (3d ed. 1989).

32. Perhaps most fundamentally, these views differ on whether the parents' claims or the child's claims are theoretically prior. See JEFFREY BLUSTEIN, *PARENTS & CHILDREN: THE ETHICS OF THE FAMILY* 104-14 (1982). It is worth noting that these discussions tend to consider the role of parents, rather than family members more generally.

33. See, e.g., *WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* (William Aiken & Hugh LaFollette eds., 1980) [hereinafter *WHOSE CHILD?*] (presenting essays on relationship between child, parent, and state).

be raised to become autonomous adults. These liberal assumptions are severely criticized, particularly by those who doubt the individualism and autonomy on which they rest.<sup>34</sup> Nevertheless, these assumptions are a useful starting place because they represent the corresponding theory about decision making for children that the prevailing liberal theory in bioethics represents about decision making for adults. So the aim in what follows is to draw out some of the implications of this liberal theory for the role of parents in making health care decisions for their children. The aim, in short, is to outline a liberal account of the role of parents in making health care decisions for their children, not to defend liberal theory more generally.

The child-centered views of parental obligations that have predominated in recent liberal political theory base parents' obligations towards their children on a vision of what their children should become: autonomous adults, capable of choosing the kinds of lives they want to lead. Joel Feinberg describes this theory as the "right to an open future."<sup>35</sup> By this, he means that children have rights to have certain "key options" continue to be available for them, such as choices of careers that fit their talents and dispositions, until they are able to make choices among them as adults. Parents, in turn, are obligated to try to create the conditions that help children realize their rights to open futures. Thus, according to the liberal view, parents are obligated to try to provide their children with the sustenance, support, and education needed for growth to autonomous adulthood.

For its critics, perhaps the most controversial aspects of this liberal view are its incompatibility with parental values and traditional forms of social life. But the theory is subject to criticism even on its own terms: the creation of the conditions for eventual self-determination may not be a value-free enterprise in itself; it may, by creating the conditions for one sort of life, effectively preclude the enjoyment of others. We might say that choices about children's lives are *neutral* towards their futures, to the extent that they leave options open for later determination by the child

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34. See MICHAEL J. SANDEL, *LIBERALISM AND THE LIMITS OF JUSTICE* *passim* (1982).

35. Joel Feinberg, *The Child's Right to an Open Future*, in *WHOSE CHILD?*, *supra* note 33, at 126; see also BLUSTEIN, *supra* note 32, at 199 (asserting that parents have duty "to expose their children to the psychological conditions that facilitate the development of their capacities for self-determination, or autonomy").

as an adult. The extent to which creation of the conditions for self-determination is neutral in this sense is highly controversial. For instance, some liberals tend to believe that this neutrality does and should have a relatively wide range.<sup>36</sup> Writers more critical of the liberal tradition are doubtful.<sup>37</sup>

Doubts about both the possibility and the desirability of neutrality are clearly illustrated by controversies about education, and these controversies are instructive for decision making about health care.<sup>38</sup> There are highly charged questions about the extent to which education that helps create the conditions for self-determination is consistent with parental influence about values. Are parents neutral if they encourage their children to love music, sports, or God? Can any of these attitudes be "revoked," and, if not, does liberal neutrality recommend confining education to bloodless values that instill no passions that the child cannot later overthrow? Would it, for example, violate a child's right to an open future to bring the child up in a very structured religion, which inculcates significant feelings of guilt for abandonment of the faith?<sup>39</sup> To limit the child's education in order to avoid contact with the "modern" world, as the Amish do?<sup>40</sup> To encourage a child to pursue competitive gymnastics, a career as a concert violinist, or some other calling that may require an overwhelming commitment from an early age? To conclude that parents may not choose any of these pathways for a child because the choice is not neutral among futures imposes drastic limits on what parents may do for their children: they cannot create deep concerns, loves, or commitments that are inconsistent with an open future. If the

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36. Feinberg, *supra* note 35, at 124-51.

37. Sharon Bishop, *Children, Autonomy, and the Right to Self-Determination, in WHOSE CHILD?*, *supra* note 33, at 154-76.

38. This is a problematic analogy for those who believe that one set of values governs education—for example, the duty to instruct children in the ways of God—but a different set of values governs health care decision making, such as the preservation of life at all costs. With views such as these, the parents are seen as agents of the values in question. The perspectives which include these values may, however, also see the parents as preferred agents for value transmission. See, e.g., *The Country's Future Is in Your House*, WASH. POST, Aug. 20, 1992, at A34 (excerpts from Barbara Bush's speech at Republican National Convention indicating that parents are most important vehicle for transmitting values to children).

39. Cf. JAMES JOYCE, *A PORTRAIT OF THE ARTIST AS A YOUNG MAN* (Penguin Books 1983) (1916) (illustrating these religious conflicts from Catholic perspective).

40. Cf. *Wisconsin v. Yoder*, 406 U.S. 205, 210-12, 236 (1972) (upholding right of Amish parents to remove their children from school after eighth grade).

right to an open future is understood to require extensive neutrality among courses that cannot later be rejected, the theory seems implausible as a complete account of the role of parents in their children's lives.

In the debates about education, however, the right to an open future is not understood in this pallidly neutral way. Suppose, then, that we try a somewhat fuller characterization of which future options should be kept open for a child. Three quite tentative suggestions can be drawn from remarks made by liberal theorists such as Feinberg. First, actions taken during childhood should not be ones that would violate the rights of the later adult. If adults generally enjoy political rights such as the right to vote, rights of personal choice such as the right to marry or to choose whether to bear children, or liberty rights such as freedom of speech, parents should not take steps during childhood that would violate these later rights. Thus, for example, parents should not be able to renounce a child's rights of citizenship.

Second, actions taken during childhood should attempt to uncover and foster a reasonable measure of the child's abilities and talents.<sup>41</sup> Thus, parents should not impose educational or work regimes that offer the child little opportunity to discover talents or that ruthlessly attempt to discourage significant abilities.<sup>42</sup> On the other hand, children are multifaceted and not all talents can be developed simultaneously; part of what is involved in the openness of the child's future is the need for guidance and selection among various possibilities for development. Parents may, along with their children as they become older, select among reasonable sets of these possibilities.

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41. Feinberg, for example, links the child's "open future" to the development of talents:

[T]he parents who raise their child in such a way as to promote his self-fulfillment most effectively will at every stage try to strengthen the basic tendencies of the child as manifested at that stage. They will give him opportunities to develop his strongest talents, for instance, after having enjoyed opportunities to discover by various experiments just what those talents are.

Feinberg, *supra* note 35, at 150.

42. On these grounds, for example, Feinberg is much more doubtful about the permissibility of the Amish decision to forego public education after the eighth grade, *Wisconsin v. Yoder*, 406 U.S. 205 (1972), than about the permissibility of Jehovah's Witnesses using their children to distribute pamphlets on street corners, *Prince v. Massachusetts*, 321 U.S. 158 (1944). See Feinberg, *supra* note 35, at 129-38.

Third, actions taken during childhood should not preclude the later adult from enjoying major life satisfactions, such as deep human relationships.<sup>43</sup> This third suggestion is difficult to formulate and to balance against the second. There are certainly tensions between them. Sharon Bishop, for example, argues that education of a female child that is aimed at developing talents is crucial for autonomy even though it may conflict with traditional female roles.<sup>44</sup> These tensions are at the heart of the dialogue about an education that develops understanding and intellectual talents, at the likely expense of deeply held communitarian values.

These three suggestions about how to understand the openness of the child's future in the context of education might be applied to medical decision making as follows. First, decisions that would violate the rights of the later adult would be prohibited. For example, if the later adult has rights to procreate, sterilization of the child would violate these rights. If the later adult has rights to nurture her own children, compelled abortion on an adolescent patient would violate those rights. Second, in making medical decisions, parents should try to the extent possible to take into account the development of reasonable groupings of children's abilities and talents. They should not, for example, deny care or delay care when to do so carries significant risks of mortality or morbidity. Nor should they choose therapies that unreasonably risk compromising cognitive capacities or major functional possibilities. On the other hand, parents may legitimately weigh risks to one sort of capacity against risks to another—for example, choices between chemotherapeutic modalities that weigh an increase in the chance of limb salvage against sterility or hearing loss. Third, parents should not make decisions, if at all possible, that are likely to preclude important human satisfactions. For example, in medical decision making they should take into account the preservation of communicative and perceptual capacities.<sup>45</sup>

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43. BLUSTEIN, *supra* note 32, at 199, argues that parents have twin duties towards their children: raising them to be capable of self-determination and promoting their self-fulfillment.

44. Bishop, *supra* note 37, at 154-76.

45. For a criticism of this suggestion and defense of the view that parents should not be required to foster the development of life prospects that they find unacceptable, see William Ruddick, *Parents and Life Prospects*, in *HAVING CHILDREN: PHILOSOPHICAL AND LEGAL REFLECTIONS ON PARENTHOOD* 124-37 (Onora O'Neill & William Ruddick eds., 1979). Ruddick gives the example of dwarf parents who very much want to raise a dwarf



These suggestions outline the latitude of parental discretion in health care decision making. They would not, for example, require parents to prolong life if doing so would not be helpful in allowing the child to develop talents or experience important life satisfactions. Thus, to this extent, parents would be permitted to make quality of life judgments for their children, including judgments to forego treatment when the prognosis is dim for the child's ability to develop talents or to experience well-being at even a minimal level. Parents would also be permitted to choose among alternate possible lives consistent with these guidelines and to weigh therapeutic alternatives in light of the different risks to functional capacities that they present. For example, parents could choose therapeutic options that risk death in exchange for significant improvements in functional status, weigh options that trade different kinds of compromises in functional status against each other (for example, surgery as against chemotherapy for certain types of cancers or choice of gender for a child born with ambiguous gender characteristics), or weigh significant compromises to well-being against other possible advantages of care.

On this understanding of the implication of liberal theory for parent-child relationships, parents thus have significant latitude in shaping the futures of their children. This latitude embodies choices among forms of health care that may shape quite different futures, including even the possibility of death. Furthermore, the role of parents is not simply informational or contingent; it is an integral part of the decision, as long as the decision is exercised in accord with the constraints suggested above, unless some circumstance disqualifies the parents as parents altogether.

### *C. Interests of the Family*

Within patient-centered models of medical decision making, the interests of the family are relevant only insofar as they make a difference to the patient's choices or interests. As other Articles

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child and refuse medical care that would cause the child to be of normal stature. He concludes that the parents are not obligated to provide the care, despite the predictability that being of normal size would open important life prospects for the child: "The parents . . . are violating the child's right to a normal life—if there is such a right. I see no basis for such a right, nor do I think this case requires us to look for one. If there is such a right, we may set against it the dwarves' right to be parents." *Id.* at 133-34.

in this symposium indicate, entirely patient-centered models may be increasingly regarded as myopic, but this is not the point here. The models of medical decision making developed in this Article are based largely on the interests of the patient, but it is important to survey briefly the separate interests of family members because they are often among the most important factors in actual decision making.

First, it is obvious that family members' medical decisions may have remarkably intense and long-lasting effects on family emotions, relations, time, opportunities, and finances. The care of a debilitated relative can be a daily intrusion on marital relationships, a drastic limit on career choices, or a perceived barrier to having (other) children. Although adoption of or reliance on alternative sources of care are readily proposed as alternatives, neither option is easily taken without emotional pain. Various social arrangements in the United States particularly complicate the burdens. For example, Medicare pays only very limited home health benefits,<sup>46</sup> and there are economic difficulties in qualifying for Social Security disability benefits.<sup>47</sup> If consequences for the family are considered relevant to health care decision making, it certainly seems that there will be cases in which the costs to the family will be so great as to outweigh any contemplated benefit of continued care for the afflicted family member.

Second, views about the moral importance of relationships may support an enhanced role of the family in medical decision making for incompetent family members. For example, if the potential for a parent-child relation is regarded as a very important object of care, then the family ought to have a role in deciding about care as it affects this relationship. For those who place the relationship rather than the individual at the center, the family is integral to the process of health care decision making.

### III. THREE DIFFERENT ROLES FOR THE FAMILY

The patient's choices, interests, and open future thus are important patient-centered characteristics that support roles for the family in making medical decisions for incompetent members.

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46. See 42 C.F.R. § 410.10 (1991).

47. See 20 C.F.R. § 416.1100-.1182 (1992).

When the aim of decision making is to attempt to capture or recapture the patient's choices, family members frequently will be important sources of information. They may know of actual choices or be able to report discussions about desires in hypothetical situations. They may be able to supply important background information about the patient's values or styles of decision making and the extent to which these have been long-lasting and consistent. On the other hand, the family may have been at worst estranged and at best simply uncommunicative about medical decision making. Thus, when there is some possibility of reconstructing the choices of a formerly competent family member, the primary role for the family is to serve as a critical source of information about the patient.

When the aim of medical decision making is realization of the patient's best interests, either because the patient's choices cannot be reconstructed or because the patient has never been competent, the family may also be an important source of information. The family may have knowledge about how intensely a patient felt various satisfactions or how much discomfort the patient apparently suffered from illness or therapeutic intervention. On the other hand, a critical part of the assessment of a patient's interests is understanding of the medical prognosis and alternatives for care, and in this respect the family is not in a privileged position. Because of its love and concern, however, the family may be the most likely agent to press for consideration—and, importantly, for reassessment and reconsideration—of the patient's interests. Thus, when the best interests standard is the most appropriate one for medical decision making, the family's principal role is as advocate for the patient's interests.

Finally, when the patient's interests have yet to be developed significantly, medical decisions may shape that development in important ways. By analogy to the role of the parent in education, parents may make some of these seminal health care decisions for their children, subject to three important guidelines. First, parents should not act in ways that violate the rights of the adult the child will become. Second, parents should try to ensure the continued availability of a life in accord with a reasonable range of the child's talents and abilities. Third, parents should try to preserve important capacities for their children to experience satisfactions. In making medical decisions for their children, therefore, the

parents' role extends to shaping, as well as advocating, the children's interests. This is particularly true for infants and younger children: as children become increasingly capable of shaping their own lives autonomously, the roles of family members increasingly shift towards their roles for adult patients.

These roles for the family—informant, advocate, and shaper—are supported within the predominant liberal paradigm of bioethics. If liberal assumptions such as the priority of the individual or the importance of autonomy are discarded, then there may be different and even stronger roles for the family.

#### IV. CURRENT LEGAL APPROACHES: THE CONTRAST BETWEEN ADULTS AND YOUNG CHILDREN

The last ten years have seen remarkable statutory and case-law development with respect to medical decision making for incompetent patients. Insofar as trends are discernable, the legal developments seem to more clearly allow discretion for familial decision making when the patient is an adult than when the patient is a young child. This divergence seems contrary to the suggestions drawn from the liberal models about the ethics of health care decision making.

##### A. Adults

With respect to adults, case law has tended to allow family members relatively wide latitude in reconstructing patients' choices. A good example is the Washington Supreme Court's decision in *Colyer*, which relied on the family's reconstruction of Bertha Colyer's values of independence and distrust of medical care.<sup>48</sup> Even the *Cruzan* case was ultimately resolved in accord with the family's wishes.<sup>49</sup> Despite the state's insistence that there be clear and convincing evidence of the patient's wishes, the trial court eventually found that the family had brought forward sufficient evidence to show that Nancy would not have wanted her

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48. *In re Colyer*, 660 P.2d 738, 748 (Wash. 1983) (en banc).

49. Diane E. Hoffman, *Introduction: The Right to Die After Cruzan*, 2 MD. J. CONTEMP. LEGAL ISSUES 93, 96 (1991).

life prolonged in a persistent vegetative state by means of medically assisted nutrition and hydration.<sup>50</sup>

In addition to the court decisions, some states now also have statutes that authorize family members to consent to the withdrawal of life sustaining treatment, most frequently when the patient is terminally ill.<sup>51</sup> These statutes typically list family members in an automatic order of priority, after the patient's own choice of a surrogate or a court appointed guardian. New York's proposal to let family members themselves select the surrogate is innovative.<sup>52</sup> Although these provisions are often part of statutes establishing living wills or special powers of attorney for health care, they typically enumerate family members by degree of relationship rather than by knowledge or known intimacy to the patient. One justification for the preset statutory priorities is that they are highly likely to mirror the justifications for reliance on the family, especially knowledge and caring. But there is no automatic requirement to ascertain whether this is so in any particular case. Instead, if there is significant disagreement with the statutory ordering of family members, the statutory alternative is to seek appointment of a court-appointed guardian who then takes priority. The most likely entity to pursue guardianship

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50. *Id.*

51. States with family consent statutes include: Arkansas (ARK. CODE ANN. § 20-17-214 (Michie Supp. 1991)); Connecticut (CONN. GEN. STAT. § 19a-571 (1991)); the District of Columbia (D.C. CODE ANN. § 21-2210 (1989)); Florida (FLA. STAT. ANN. § 765.07 (West 1986)); Hawaii (HAW. REV. STAT. § 327D-21 (1991)); Idaho (IDAHO CODE § 39-4303 (1985) (medical consent statute)); Illinois (ILL. ANN. STAT. ch. 110½, para. 851-25 (Smith-Hurd Supp. 1992)); Indiana (IND. CODE ANN. § 16-8-12-4 (Burns 1990), construed in *In re Lawrence*, 579 N.E.2d 32, 41-43 (Ind. 1991)); Iowa (IOWA CODE ANN. § 144A.7 (West 1989)); Louisiana (LA. REV. STAT. ANN. § 40:1299.58.5 (West 1992)); Maine (ME. REV. STAT. ANN. tit. 18-A § 5-707(b) (Supp. 1991)); Maryland (MD. CODE ANN., HEALTH-GEN. § 20-107(d) (Supp. 1991) (medical consent statute)); Mississippi (MISS. CODE ANN. § 41-41-3 (Supp. 1991) (medical consent statute)); Montana (MONT. CODE ANN. § 50-9-106 (1991)); Nevada (NEV. REV. STAT. ANN. § 449.626 (Michie 1991)); New Mexico (N.M. STAT. ANN. § 24-7-8.1 (Michie 1986)); New York (N.Y. PUB. HEALTH LAW § 2965 (McKinney Supp. 1992) (limited to DNR orders)); North Carolina (N.C. GEN. STAT. § 90-322 (1990)); Oregon (OR. REV. STAT. § 127.635 (1991)); South Dakota (S.D. CODIFIED LAWS ANN. § 34-12C-3 (Supp. 1992) (medical consent statute)); Texas (TEX. HEALTH & SAFETY CODE ANN. § 672.009 (West 1992)); Utah (UTAH CODE ANN. § 75-2-1107 (Supp. 1992)); Virginia (VA. CODE ANN. § 54.1-2986 (Michie Supp. 1992)); and Washington (WASH. REV. CODE ANN. § 7.70.065 (West 1992)) (medical consent statute).

52. NEW YORK STATE TASK FORCE, *supra* note 2, app. A, at 253.

proceedings is the treating health care institution, motivated by fears of liability when family members disagree.<sup>53</sup>

### *B. Children*

The legal situation for children is less developed and more diverse. Some of the earlier cases appeared to be moving towards the view that parents may not refuse life-saving treatment but have latitude to make decisions when there is some dispute about what is in their children's interests. Other cases, however, gave parents more latitude, particularly several highly controversial instances in which corrective surgery was withheld from infants with Down's syndrome. In the early 1980s, the Baby Doe regulations took a strong stand in favor of aggressive treatment of nearly all newborns.<sup>54</sup> Perhaps because of the regulations, case-law development was notably limited. Several states passed statutes codifying the Baby Doe regulations;<sup>55</sup> in most others, the legal status of parental decisions to withhold or withdraw care remains unclear.

#### *1. Before Baby Doe*

By the late 1970s, case law had appeared with respect to nontreatment decisions for infants and children. For the most part, the decisions involved parents who had refused standard medical recommendations on religious grounds.<sup>56</sup> When there was medical agreement that the recommended care had the clear potential to avoid mortality or morbidity, courts generally would mandate it.<sup>57</sup> Several cases left decisions within the parents' discretion

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53. ALAN MEISEL, *THE RIGHT TO DIE* § 6.1-27 (1989 & Supp. 1991)).

54. See *infra* notes 79-86 and accompanying text.

55. See *infra* notes 91-101 and accompanying text.

56. See MEISEL, *supra* note 53, § 13.5-6.

57. *E.g.*, *Morrison v. State*, 252 S.W.2d 97, 103 (Mo. Ct. App. 1952) (holding that state has authority to mandate blood transfusion to preserve child's life); *State v. Perricone*, 181 A.2d 751, 756-57 (N.J. 1962) (affirming order of blood transfusion for infant over Jehovah's Witness parents' objection); *Sampson v. Taylor (In re Sampson)*, 278 N.E.2d 918, 919 (N.Y. 1972) (holding religious objection by parent to blood transfusion was not bar to court order in neglect proceeding when transfusion was necessary to success of required surgery); *Application of Brooklyn Hospital*, 258 N.Y.S.2d 621, 623 (Sup. Ct. 1965) (granting hospital administrator authority to consent to child's blood transfusion when child was seriously endangered and parents objected to

when the court perceived significant dispute about the possible efficacy of the care or likely risks to the child.<sup>58</sup> Although relatively sparse, these cases seem to track the liberal view sketched above:<sup>59</sup> parents may choose among reasonable courses of action in shaping their children's futures, but they may not take avoidable risks of cutting off significant capacities or even life itself.

The relatively undeveloped state of the law was highlighted by two much discussed cases in 1979. In Massachusetts, the Chad Green case involved a parental decision to discontinue chemotherapy in favor of giving laetrile to their young son with leukemia.<sup>60</sup> Chad Green was twenty months old when his disease was first diagnosed; the treating physicians recommended chemotherapy with an apparent prognosis of a better-than-fifty-percent likelihood of five-year survival. The risks of chemotherapy, as described by the physicians, were relatively benign, easily managed side effects such as constipation. The parents, however, were very upset by the way the chemotherapy made their son feel and discontinued it.

The court ordered the parents to provide the care,<sup>61</sup> but the reasoning in the case was less than fully clear. In the first hearing, in which the state sought to compel continued therapy, the court balanced three factors: the natural rights of parents, the best interests of the child, and the interests of the state.<sup>62</sup> The factors were presented as a list, without a theoretical account of which should predominate or why. The court's decision rested on the conclusion that each of the factors pointed in the same direction. The rights of the parents, in the court's view, were to be treated as a trust which did not extend to the right to risk the life

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transfusion on religious grounds); *In re Clark*, 185 N.E.2d 128, 132 (Ohio C.P. 1962) (stating that when child's right to live and parents' religious beliefs collide, former is paramount).

58. *E.g.*, *In re Seiferth*, 127 N.E.2d 820, 824 (N.Y. 1955) (allowing parents to decide about child's cleft palate surgery); *In re Hudson*, 126 P.2d 765 (Wash. 1942) (discussing amputation of grossly deformed arm to which parents objected because of risks of surgery). It may be significant that these are older cases, and the courts were less inclined to view medical care itself in a favorable light.

59. *See supra* notes 31-45 and accompanying text.

60. *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978).

61. *Id.* at 1062.

62. *Id.* at 1061-67.

or health of the child.<sup>63</sup> The best interests of the child would clearly be served by therapy: the chemotherapy had minimal side effects (so the court found) and offered a good chance of cure; moreover, there were no other available alternatives.<sup>64</sup> And the state's interest was to protect the child.<sup>65</sup> In a later hearing, the court used the same analysis to order the parents to discontinue therapy with laetrile and vitamins in addition to ordering the chemotherapy.<sup>66</sup> This second conclusion illustrates the difficulty with the court's approach because the evidence about the risks of the supplemental therapy was quite thin, and the parents' hopes were simply set aside.

On the other hand, balancing the parents' rights against the child's interests can also lead to problematic latitude for parents. In a New York case parallel to the Chad Green fact situation, the court permitted the parents of a seven-year-old with Hodgkin's disease to refuse chemotherapy in favor of laetrile on the recommendation of a licensed New York physician who specialized in nutrition.<sup>67</sup>

The difficulty with listing the parents' rights along side the child's interests is starkly illustrated by a second decision in 1979, the California case of Phillip Becker. Born with Down's syndrome and a heart defect, Phillip Becker, at twelve years old, faced the prospects of increasing shortness of breath and ultimate lung failure by early adulthood if he did not have surgery to repair the heart defect.<sup>68</sup> Although the surgery had been recommended for several years, Phillip's parents refused their consent. The State petitioned for Phillip to be declared a dependent child of the court for the purpose of surgical consent. Despite Phillip's natural parents' failure to maintain extensive contact with him,<sup>69</sup> the court rejected the State's petition and allowed the parents to

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63. *Id.* at 1063.

64. *Id.* at 1065.

65. *Id.* at 1066-67.

66. *Custody of a Minor*, 393 N.E.2d 836, 845-46 (Mass. 1979). The court concluded that the laetrile and vitamin therapy put the child at risk of low-grade cyanide poisoning and brain damage. *Id.* at 845. By the time the court actually heard the case, the parents had fled with the child. *Id.* at 838 n.1.

67. *Saratoga County Dep't of Social Servs. v. Hofbauer (In re Hofbauer)*, 393 N.E.2d 1009, 1012-15 (N.Y. 1979).

68. *Bothman v. Warren (In re Phillip B.)*, 156 Cal. Rptr. 48, 50 (Ct. App. 1979).

69. *Herbert H. v. Warren B. (Guardianship of Phillip B.)*, 188 Cal. Rptr. 781, 786-87 (Ct. App. 1983).



refuse the surgery.<sup>70</sup> The court began its analysis with the autonomy rights of the parents:

Inherent in the preference for parental autonomy is a commitment to diverse lifestyles, including the right of parents to raise their children as they think best. Legal judgments regarding the value of childrearing patterns should be kept to a minimum so long as the child is afforded the best available opportunity to fulfill his potential in society.<sup>71</sup>

At the same time, according to the court, the state has an interest in protecting children, and may thus interfere in family matters "to safeguard the child's health, educational development and emotional well-being."<sup>72</sup> The trial court denied the petition because the evidence did not show clearly and convincingly that the surgery was necessary to safeguard Phillip's health.<sup>73</sup> In affirming the trial court's decision, the appellate court agreed that the clear and convincing standard was proper.<sup>74</sup> Testimony at the trial court included evidence that the surgery was somewhat more risky for Down's syndrome patients than for other children (for whom it had a five to ten percent mortality risk), that there was the possibility of complications requiring a pacemaker, and that Phillip already might have suffered some lung damage from his heart condition. The appellate court characterized the trial court as balancing the benefits and risks of the surgery for Phillip,<sup>75</sup> a characterization that has been criticized as slanted towards the parents' conclusions.<sup>76</sup>

Intermittently throughout the 1970s, reports appeared about parental decisions to withhold care from ill newborns. A study of medical practice indicated that a number of infants with Down's syndrome or neural-tube defects died after nontreatment deci-

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70. *Phillip B.*, 156 Cal. Rptr. at 52.

71. *Id.* at 51.

72. *Id.*

73. *Id.* at 52. The state, however, had urged the lower "preponderance of the evidence" standard. *Id.*

74. *Id.*

75. *Id.*

76. See generally Kathleen M. Heydon, Note, *Guardianship of Phillip B.: Nonparents' Right to Custody in California*, 18 LOY. L.A. L. REV. 779 (1985) (discussing history of Phillip Becker and analyzing court decisions).

sions.<sup>77</sup> Several highly publicized parental decisions to refuse care—especially the "Baby Doe" cases—brought the issue into the political forum. Several factors may have combined to explain the aggressiveness of the Baby Doe regulations: the growth of the right to life movement, the Reagan presidency, the uncertainty of case law, and changes in attitudes and understanding about Down's syndrome patients.<sup>78</sup>

## 2. *The "Baby Doe" Regulations*

Promulgated first under section 504 of the Rehabilitation Act,<sup>79</sup> and then under the Child Abuse Amendments,<sup>80</sup> the Baby Doe regulations set very stringent limits for decisions with respect to handicapped newborns. The regulations base decision making about care almost entirely on the likelihood of whether treatment will contribute to the survival of the impaired newborn. The regulations absolutely prohibit any consideration of likely quality of life for the infant.

Under the regulations, there are only three circumstances in which care may be withheld from a handicapped newborn:

(1) If, in reasonable medical judgment, the child is chronically and irreversibly comatose;<sup>81</sup>

(2) If, in reasonable medical judgment, the care would only prolong dying—that is, it would not be effective in ameliorating all of an infant's life-threatening conditions or otherwise would be futile in terms of survival;<sup>82</sup> or

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77. Raymond S. Duff and A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890, 892-94 (1973).

78. For a description of the context, see MEISEL, *supra* note 53, § 14.6-7.

79. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 394 (1973) (codified as amended at 29 U.S.C.A. § 794 (Supp. 1992)).

80. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749-64 (1984) (codified in scattered sections of title 29 U.S.C.A.). The regulations were originally promulgated under § 504 of the Rehabilitation Act in response to two highly publicized cases of withholding of medical treatment for handicapped newborns. See *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 617-23 (1986). The Supreme Court held that the regulations had been improperly promulgated under the Rehabilitation Act. *Id.* at 647. A second round of "Baby Doe" regulations, adopted under the Child Abuse Amendments, require states to protect infants with life-threatening conditions from "medical neglect" in exchange for receiving child abuse prevention funding. See 45 C.F.R. § 1340.1-.20 & app. (1991).

81. 45 C.F.R. § 1340.15(b)(2)(i) (1991).

82. *Id.* § 1340.15(b)(2)(ii).

(3) If, in reasonable medical judgment, the care would be virtually futile in terms of survival and under the circumstances would be inhumane.<sup>83</sup>

In addition, there are no circumstances under which nutrition, hydration, or comfort care may be withheld, despite the infant's prognosis.<sup>84</sup>

These regulations impose remarkable limits on family decision making with respect to handicapped newborns. They express a commitment to the preservation of life in nearly all circumstances, which is clearly at odds with the liberal account sketched above. They do not allow parents to consider whether death is preferable to continued existence with truncated capacities, except in the case of chronic coma. Nor do the regulations allow parents to forego inhumane treatment, unless it would be virtually futile in terms of survival.

The Baby Doe regulations apply to states that choose to receive federal funding for their programs to prevent child abuse. In order to receive the funding, states are required to have statutory definitions of child abuse, including medical neglect, that roughly track the regulations.<sup>85</sup> A few states have chosen to forego the funding.<sup>86</sup>

### 3. *The Current Confusion*

Case law after the Baby Doe regulations is very limited. Three reported appellate decisions have involved parental requests to withdraw care.<sup>87</sup> In each case, the patient was an infant, chronically comatose, and had no likelihood of recovering any cognitive function. In all of the cases, the court permitted discontinuation of the care. In one case, the court specifically described the discontinuation as permissible because the infant was both irretrievably comatose and "terminally ill," despite indications that the infant could live from one to five years with aggressive

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83. *Id.* § 1340.15(b)(2)(iii).

84. *Id.* § 1340.15(b)(2) & app.

85. *Id.* § 1340.14(b).

86. See Terry J. Barnett, *Baby Doe: Nothing to Fear But Fear Itself*, 10 J. PERINATOLOGY 307, 310 (1990).

87. *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982).

supportive therapy.<sup>88</sup> In a second case, the court concluded specifically that the state's "Baby Doe" law permitted the discontinuation of therapy in cases of irreversible coma.<sup>89</sup> Meisel has argued that these decisions are not limited to allowing parental discretion when the child is terminally ill and comatose and that the situation for children appears to be developing in parallel to the situation for adults.<sup>90</sup> The utter paucity of cases involving children, however, together with the quite explicit language in these cases about the child's comatose and terminal condition, suggest that Meisel's conclusion is unduly optimistic.

Indeed, state statutes also appear to leave parents and the health care profession in uncertainty about whether parents have the power to discontinue care in cases that do not meet the strict Baby Doe criteria (or their analogues for older children). Some states give parents the power to consent to health care for their children but are silent about whether this includes the power to make nontreatment decisions.<sup>91</sup> A number of states define child abuse or neglect generally to include the failure to provide needed medical care.<sup>92</sup> Some explicitly provide that religiously motivated failure to seek care is not criminal child abuse.<sup>93</sup> Yet none of these state child abuse statutes have dealt with whether nontreatment decisions in cases of medical disagreement or uncertainty should be viewed as the failure to provide needed care.

Five states have spelled out explicit limits on the power of parents to discontinue care.<sup>94</sup> One of these statutes, Minnesota's, specifically tracks the Baby Doe regulations.<sup>95</sup> Louisiana prohibits any decision to deprive a child of nutrition, hydration, oxygen, or comfort care with the intent to cause or allow the death of the

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88. *Barry*, 445 So. 2d at 370-71.

89. *P.V.W.*, 424 So. 2d at 1021-22.

90. MEISEL, *supra* note 53, § 13.7-.8.

91. *E.g.*, CAL. CIV. CODE § 25.8 (West 1982); UTAH CODE ANN. § 76-14-5(4)(a) (1983) (malpractice statute).

92. *E.g.*, ALA. CODE § 26-14-1(2) (1986); ALASKA STAT. § 47.10.010(2)(B) (1990); UTAH CODE ANN. § 76-5-110(1)(d) (1990).

93. *E.g.*, ALA. CODE § 26-14-1(2) (1986); ARK. CODE ANN. § 5-27-221(c) (Michie 1987); CAL. PENAL CODE § 11165.2 (West 1992); MASS ANN. LAWS ch. 273, § 1 (Law. Co-op. 1992).

94. See *infra* notes 95-101 and accompanying text (discussing the five states' limits on parents' power to terminate care).

95. MINN. STAT. ANN. § 260.015(5) (West 1992).

child.<sup>96</sup> Louisiana also prohibits the intentional deprivation of care that is "necessary to attempt to save the life of the child in the opinion of a physician exercising competent medical judgment," with three exceptions: profound and irreversible coma, a condition that will be terminal despite "every appropriate medical treatment," or care with potential risks that outweigh the potential benefits for survival.<sup>97</sup> Louisiana is the only state with a specific provision for parents to execute directives to withdraw or withhold care for ill children when the child's condition falls within the statutory provisions.<sup>98</sup> Like the Baby Doe regulations, Louisiana's statute asserts a preference for the preservation of life except when all cognitive capacity has been lost. Two states, Rhode Island and Indiana, provide that parents may not withhold nutrition, medical treatment, or surgical intervention to a handicapped child if that care is generally provided to similarly situated children without handicaps.<sup>99</sup> Finally, Arizona requires parents to provide medically necessary treatment for their children but exempts care that is not necessary to save life or that will only prolong the process of dying.<sup>100</sup>

Another entirely uncharted area in health care decision making for children is the role of family members other than parents. Unlike the family consent statutes for adults, the statutes described above generally deal only with parents or guardians. Meisel reports that in practice when parents are not available to make decisions for their children, attending physicians turn to other available family members, much as is done for adults. But there is no legal authority for this practice, either in case law or statute, and Meisel cites none.<sup>101</sup>

## V. CONCLUSION

Thus, the legal picture of the role of families in health care decision making is quite different for children than for adults. For

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96. LA. CHILDREN'S CODE art. 1553 (West Supp. 1992).

97. *Id.* art. 1554(1)-(3).

98. *See id.* art. 1557.

99. IND. CODE ANN. § 31-6-4-3(f) (Burns Supp. 1992); R.I. GEN. LAWS § 40-11-3(b) (1990).

100. ARIZ. REV. STAT. ANN. § 36-2281 (1986).

101. MEISEL, *supra* note 53, § 13.3.

adults, the law is increasingly authorizing family members to act for incompetent relatives. For children, the law is far more diverse. Parents are required to provide necessary medical care for their children, and in some states, they are specifically authorized to consent to health care on their children's behalf, but what these provisions mean is unclear. Case-law development has been largely cut off in the wake of the right-to-life perspective of the Baby Doe regulations. Other family members are almost entirely left out of the legal picture.

Yet if the liberal view of health care decision making is of interest—and, whatever its merits, it is the predominant view in bioethics today—this legal picture is backwards. Within this liberal framework, the roles of families for adult patients are principally reporting and implementing the patient's own choices or advocating for the patient's best interests. The role of parents in making decisions for their children, however, may extend to decisions which, within limits, shape their children's futures. Yet, under current law, families are given greater latitude in decision making for incompetent adults than for their children. Perhaps this conclusion shows that the liberal picture itself is flawed. Or perhaps it shows that the intervention of the Baby Doe regulations has unfortunately truncated development of legal understanding of the authority of parents to make health care decisions for their children.